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Review of Organ and Tissue Donation Procedures

Response from: John Peacock, Liver Recipient
August 10, 2008

This response is based on my experiences as a recipient, not on the basis of my role as president of Transplant Australia in Queensland. Although, my position has afforded me a wider view as I am in regular contact with both donors, and recipients.

Background:

In December 2005 as a response to what appeared to be heart attack symptoms I presented to Wesley Hospital's emergency department. I was eventually diagnosed with severe liver disease and recommended to a gastroenterologist.

After 3-4 months treatment I was advised that I had "end stage" liver disease and would require a "transplant". Subsequent investigation by my wife and I confirmed that this was probably the only course available to us and so we began the process leading to getting onto the waiting list. This process, amongst other quite frightening "issues" that are to be faced, include the fact that rather than be secure in the knowledge that you can be "treated" you will in fact be "lucky" to receive a transplant at all.

I was lucky and by October 2005 had received a transplant and have enjoyed fantastic health since.

My wife and I have since become involved in the transplant sector working as volunteers for Transplant Australia in a number of different areas. So that we may speak with confidence about transplantation and the process "end to end" we have undertaken some research into organ transplantation, in particular livers, due to my experience.

Our research included lengthy discussions with Queenslanders Donate, discussions and extended contact with transplant surgeons and discussions with other recipients. We also noted statements and comments from various web sites associated with the sector including Australians Donate, Sharelife, Zaidee Foundation and Transplant Australia. We have reviewed facts and recommendations made in the National Clinical Task Force Report on Organ and Tissue Donation 2008.

Opinion:

In my work with Transplant Australia I have met and talked to many organizations such as Rotary Clubs, Probus and various church and social groups. Also, our committee members regularly talk to the community at our "awareness days" from our Teamlife stand and I have met with potential and committed sponsors of the Transplant Games and in volunteer work in other arenas, discussed the issue of donation rates in Australia and the statistical success we enjoy in transplantation outcomes.

In almost all these discussions there seems to be an overwhelming agreement that we should adopt an “opt out” process. When I go on to explain, that in my opinion we almost “have” an opt out system due to the fact that we “assume” every potential donor (family) is asked (to donate) therefore they must “opt out” if they don’t wish to proceed, the discussion turns to the question of why we don’t have enough donors.

I believe the question is answered well enough in the National Clinical Task Force Report. There are many factors including our highly successful medical practitioners and hospitals whose skills and dedication save many lives, through to the exacting process of typing and matching donors.

I am not convinced however, that every potential donor family is approached and unsure how you would establish that statistic. I am also convinced that many potential donors decline through lack of information or family miscommunication or misconceptions.

I note from the Task Force Report that there are 51 recommendations that can be very broadly broken into 3 components,

1. Legislative Reform
2. Information Systems Reform and Development
3. Education

I am interested in discussing point 3, the Education component.

Recommendation:

I would urge Queensland to be pro active in implementing all these recommendations and be seen as a leader in Australia in meeting these commitments. But I also believe we need to consider how the educational component of these recommendations can be implemented, the “Act Local” segment.

In my discussions in the community there are always stories of friends or associates that have a story to tell about a belief that if you are unfortunate enough to find your self in a critical condition in a hospital that doctors wont save you because they need a donor, or the body gets mangled, or even people confusing donation with medical research in universities.

Clearly there must be an extensive, consistent, pervasive and accurate education campaign conducted in Australia, and in our case, Queensland to highlight the benefits of transplantation, demonstrate the success of transplants and the “real” story in terms of when and why donation can occur and to dismiss the myths once and for all.

I believe a national, intensive campaign along the lines conducted by Governments to encourage the wearing of seatbelts, discouraging drink driving and the Quit campaign to smokers is required. A campaign, conducted over an extended period of time with the aim to “normalize” donation as a socially positive and caring thing to do.

Secondly the success of transplantation has to be reinforced through the participation of recipients who recover their lives, stay fit and healthy and in some cases are motivated to assist in delivering this message, primarily because they realise how lucky they are to be alive.

Education must also begin at home and in schools from a very early age, it may well take a generational change to bring about a significant increase in donation.

On the issue of financial incentive to donate, I think it would work in a contrary manner to achieving the outcome of a public that considers organ donation a socially responsible and caring act. Being paid to donate organs raises a number of issues such as possibly challenging the integrity of the donor and family, who receives the payment and who can make a claim on the payment and potential exposure to unlawful trade in organs.
On the other hand I have personally witnessed the hardship for recipients and their families before and after transplantation living away from home, on the waiting list and having children and families to care for so perhaps there is scope for assistance in these areas.

In regards to presumed consent I am not sure how this could work given that there still needs to be a discussion with the family or loved ones prior to such action, and that if there is real opposition to organ removal I don't see how you can override such feelings, from a moral, or legal standpoint. A program to engage families to discuss the issue as a unit, cater for this in the Medicare forms and build consent into everyday family planning activities will bring about change.

On the other hand, where a donor has expressed a wish to donate, no other person, I believe has the right to override that decision. The current Organ Donor Register, www.donorregister.com.au and the Medicare Organ Donor register forms cater for this decision but may need legal reinforcing in a similar manner to a Will or like device.

Conclusion:

As the National Clinical Taskforce on Organ and Tissue Donation Final report 2008 concludes there are 51 recommendations that should be adopted Federally and Locally that encompass legislation, Information Systems and Education that are far reaching reforms and processes that will bring this issue to the forefront of Australian society and has the potential to drastically improve our capabilities to improve the health of many and indeed save many Australian lives.

John Peacock